



## Minutes of the Sixty-ninth Meeting of the Advisory Committee on Assisted Reproductive Technology

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Held on 27 October 2017, at the Miramar Golf Club, Wellington

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### **Present**

Gillian Ferguson (Chair)  
Mike Legge (Deputy Chair)  
Jonathan Darby  
Colin Gavaghan  
Kathleen Logan  
Sue McKenzie  
John McMillan  
Catherine Poutasi  
Sarah Wakeman

### **Non-members present**

Judge Andrew Becroft (from 12.30 pm to 2 pm)  
Stewart Jessamine, Ministry of Health (from 9.45 to 10.30 am)  
Martin Kennedy, ACART Secretariat  
Hayley Robertson, ACART Secretariat  
Michelle Stanton, ECART (from 9.25 am)

**1. Welcome**

1.1 The Chair welcomed the Committee members. She also welcomed Hayley Robertson who has re-joined the Secretariat after spending 18 months in another part of the Ministry of Health.

**1.a Opening comments**

1.2 The Chair commented that the new Government and the changes to the Secretariat might result in some changes to ACART's work programme.

1.3 The Chair also commented on the need for ACART to consider potential barriers to implementation of its recommendations, and there was a discussion about the importance of the Government acting on advice from ACART. Given that the Ministry of Health cannot always respond to ACART, ACART could consider focusing on providing advice that does not require substantial advice or policy work in response. ACART could investigate non-regulatory solutions to the matters it believes need to be addressed.

**Monitoring**

1.4 Members discussed the need for ACART to stay up to date with developments in fertility, whether they are technological or social, and to consider the implications of them. There were suggestions about how ACART can best do this and the following actions were agreed.

**Actions**

- *Members will e-mail the Secretariat, stating their areas of interest.*
- *The Secretariat will write a paper for the December meeting, suggesting a process for members to agree, that will ensure all members are up to date on important developments.*

**2. Apologies**

2.1 Barry Smith

**3. Approval of the agenda**

3.1 Members approved the agenda.

**Action**

- *Place the October 2017 agenda on ACART's website.*

**4. Declarations of Interests**

4.1 These had previously been circulated. There were no amendments.

**5. Minutes of ACART's meeting of 11 August 2017**

5.1 The minutes were approved with no amendments.

**Action**

- *Place the August 2017 minutes on ACART's website.*

**6. Actions arising from the previous minutes**

6.1 Members noted the status of actions.

**7. Work programme**

7.1 Members noted the status of actions arising from the August 2017 meeting.

**8. Meeting dates for 2018**

8.1 Members agreed the meeting dates for 2018 will be:

- Friday, 9 February
- Friday, 6 April
- Friday, 8 June
- Friday, 10 August
- Friday, 19 October
- Friday, 14 December.

8.2 Members did not set specific dates for the working group meetings but noted the following dates as diary placeholders.

- Friday, 9 March
- Friday, 11 May
- Friday, 13 July (during the school holidays. 20 July could be an alternative)
- Friday, 14 September
- Friday, 9 November.

**9. Membership changes: for noting**

9.1 Members noted that Dr Karen Reader will take up the position as the member with specialist knowledge in human reproductive research when her term begins on 1 December 2017.

9.2 Members unanimously agreed that Mike Legge should continue in his role as Deputy Chair until his term ends in April 2018. His term had recently been extended, hence the need for his role of the Deputy Chair to be considered.

9.3 As Mike's term will end in April 2018 it would be helpful to agree a new Deputy Chair to replace him before that date. The Secretariat will add an item to the agenda for February 2018, to agree a new Deputy Chair.

**Action**

- *Add an item to the agenda for February 2018, to agree a new Deputy Chair.*

**10. The Ministry's restructure and the implications for ACART**

10.1 There was a discussion about the forthcoming move of the ACART Secretariat out of the Strategy and Policy business unit into the Protection, Regulation and Assurance (PRA) business unit. A new "ethics group" is being formed in the PRA business unit comprising the secretariats from the ACART, NEAC, ECART and HDEC committees. Members agreed to write to the Ministry of Health about some

matters of concern, in particular the extra functions being assigned to the group, the potential reduction in Secretariat support, the potential conflicts of interest, and the fact that ACART is a policy committee rather than an ethics committee.

- 10.2 Dr Stewart Jessamine, manager of the PRA business unit, joined the meeting and discussed this matter. The Chair noted ACART's disappointment that there had been no consultation with the Committee on the restructure, contrary to the previously agreed process. Stewart explained the reasons for the changes and how he expects the new arrangements will work. Stewart and the ACART members agreed the ACART and ECART committees should continue to operate separately, including at the Secretariat level. They also discussed how the Ministry would manage the potentially difficult situation of Secretariat staff writing the Ministry's parallel advice when that advice might be contrary to ACART's advice.
- 10.3 Stewart and the members agreed that a planning session would be needed. The session would allow all of the committees and the Ministry of Health to set out all of their functions in order to discuss how the new ethics group could carry out those functions. (See also item 18, below, for an action on ACART considering its programme and priorities.)

#### **Action**

- *Write to the Ministry of Health about some matters of concern, in particular the extra functions being assigned to the group, the potential conflicts of interest, and the fact that ACART is not an ethics committee it is a policy committee.*
- *(Also see the final action in item 18.)*

### **11. Briefing to the incoming Minister**

- 11.1 Members noted the draft BIM, from ACART to the new Minister, is almost complete. The additions and changes set out in the following actions were agreed.

#### **Actions**

- *The Secretariat to update paragraphs 25 and 39 to account for the changes to the Secretariat.*
- *John McMillan to send the Secretariat wording for paragraph 5.*
- *The Secretariat to add a definition of "established procedures" to paragraph 5 or 6.*
- *Add a comment in the first few paragraphs about the need for ACART and ECART to be independent of one another.*
- *Circulate the revised draft to all members.*

### **12. Report from the FSA conference**

- 12.1 John McMillan thanked members for supporting his attendance at the recent FSA conference and he commented on the most significant points. He noted that the Victorian Assisted Reproductive Treatment Authority carries out a wide range of

activities, some of which ACART could learn from. John had provided a written report to members before this meeting.

- 12.2 John commented on whether some fertility treatments could or should be regulated and whether there might be scope in New Zealand for some treatments that are not established procedures to become so. For example, it might be that, with suitable guidance, clinics could extend the storage of gametes without needing approval from ECART. John also commented on gender identity and if and how ACART might investigate and advise on that.

### **13. Review of the guidelines for posthumous reproduction**

- 13.1 The committee considered the current version of the discussion document.
- 13.2 Gillian explained the recent working group discussions, in particular noting that the initial consultation will only ask about the collection of gametes from incapacitated individuals, whose death is imminent, rather than all comatose individuals or individuals in a permanent vegetative state.
- 13.3 There was a discussion about some key points needing to be briefly but clearly stated in the consultation document. For example, the document should state the policy rationale for including a limited group of incapacitated individuals (i.e. death is imminent and collection of the gametes is a matter of urgency), and clarify that the person from whom the gametes are taken will be deceased at the time when those gametes are used. It would be useful to have a brief summary in the consultation of how the tissue would be collected, and why it is best to do so while the person is still alive.
- 13.4 Members discussed the timing of the consultation and agreed that mid November 2017 to February 2018 would be suitable. This would provide enough time to account for the summer break during which some people will not be able to make submissions. Members also agreed that testing the questionnaire on colleagues would be a good way to ensure the document and questions are fit for purpose, particularly as a new Likert Scale approach is being used. Members noted the importance of ensuring confidentiality of the draft questionnaire. Plans to ask school children, over the age of 14, about the topic are also underway, and ethical approval will be sought from the New Zealand Ethics Committee.
- 13.5 Near the end of this discussion the Children's Commissioner, Judge Becroft, arrived and joined the conversation. He was particularly interested to know that ACART intends to seek comments from school children and encouraged ACART to continue to do so in future consultations. Judge Becroft also noted that it would be good for ACART to go back to the children, and let them know the outcome.

#### **Actions**

- *The Secretariat to amend the consultation document as discussed and send to the working group.*
- *The working group to suggest any changes for the Secretariat to make.*

- *The Secretariat to send the amended document to all members for their comments.*
- *The Secretariat to obtain ethical approval before consulting school age children.*
- *Once members have agreed to the document the Secretariat is to send it to the Ministry of Health for peer review and formatting.*

#### **14. Review of the donation guidelines**

- 14.1 The Secretariat summarised the progress so far in the consultation, noting that there had been meetings with several clinics and that several written submissions had also been received. The Secretariat explained that the public meetings and a hui were yet to come as well as meetings with two more clinics and one government department.
- 14.2 Members noted that a former member of the ACART Secretariat (Betty-Ann Kelly) had made a written submission. It was further noted that Ms Kelly had undertaken editorial work on the consultation paper, in her capacity as a contractor.

#### **15. Human reproductive research and ACART projects**

- 15.1 Members discussed a draft briefing to the new minister that would supplement the Briefing to the Incoming Minister (BIM). This supplementary briefing would provide the new Minister with more detail about the reasons for reviewing the guidelines on human reproductive research.
- 15.2 The discussion covered the likely timing of the briefing — ACART will send its BIM in mid-November and the minister will need time to consider it. ACART will then send the supplementary briefing in December.
- 15.3 The cover letter that will accompany the BIM should advise the Minister that ACART will send him or her the more detailed briefing about human reproductive research in December. The cover letter will also inform the Minister about the changes in technology and that the government will need to respond to some of these changes in the near future.
- 15.4 Some changes to the briefing were requested.

#### **Actions**

- *The Secretariat to amend the briefing as discussed and include in the agenda pack for December.*

#### **16. The ANZARD Report**

- 16.1 Members noted the report and asked whether it would be possible to obtain key data for Australia so that comparisons could be made. Members also agreed that the Secretariat should enquire about obtaining data on the number of women having IVF treatment (the report currently presents the number of cycles).

16.2 Members agreed the recent report should be published.

### **Actions**

- *The Secretariat is to publish the report.*
- *The Secretariat is to ask the UNSW about obtaining data on the number of women having IVF treatment and if so what it would cost.*
- *The Secretariat is to ask the UNSW about whether it would be possible to obtain key data for Australia and if so what it would cost.*

## **17. Report on ECART's August meeting**

17.1 Members noted the report.

17.2 Gillian explained that the batch of applications on which ECART had sought advice from ACART in 2017 were not included in this report. ECART has made decisions on those applications and details will be provided in ACART's December agenda pack. (See item 19, below, for commentary about the process for responding to ECART requests for advice.)

17.3 There was a brief discussion about the types of applications ECART receives and members noted that occasionally a couple would enquire about using a donated embryo, if one of the intending parents cannot use his or her own gametes, so that both of them would be equally not genetically related to the child. Members noted this issue was relevant to proposals raised in the donations consultation paper.

## **18. ACART's annual report for 2016/17**

18.1 The Secretariat advised members that the draft report was almost complete, with the outstanding material being the Chair's foreword and the ECART data for the 2016/17 financial year.

18.2 Members asked that commentary be added to draw attention to the outstanding policy work for the Ministry of Health on how disputes about embryos could be resolved. That topic had come up during ACART's work on informed consent.

18.3 The discussion returned to the matter of ACART's work programme and how the programme can be continued in the new ethics group. Members agreed to discuss the matter at the December meeting, so that they can then discuss it with the Ministry of Health, and asked the Secretariat to prepare a paper.

### **Actions**

- *The Chair will draft the foreword and seek the previous Chair's agreement to it. (The previous Chair's term covered almost all of the reporting period.)*
- *The Secretariat to obtain the data on ECART applications and add it to the report.*
- *The Secretariat to add text about the need for the policy work on resolving disputes about embryos.*

- *The Secretariat to write a paper setting out a) ACART's current projects, b) its projects under development, and c) the policy work that arises from ACART's advice. The paper should also set out all of the standing items on ACART's programme (i.e. the non-project work).*

## **19. Correspondence and enquiries**

19.1 Gillian advised members that she and the chair of ECART had discussed the process for ACART to respond to requests from ECART for advice and how that advice could be given in future. The process suggested was that the Chair and Deputy Chair of ACART and one member, with expertise in the area in question, could discuss enquiries out of session and write a response to ECART. Members agreed with this proposal.

19.2 Members noted the other items of correspondence.

## **20. Governance**

### **20.a Chair's report**

20.1 The Committee noted the report.

## **21. Secretariat report to ACART**

21.1 The Committee noted the report.

### **Extra item I**

- Members discussed the administrative support and noted that members who receive their agenda packs by rural delivery sometimes do not receive their packs until up to 5 days after they are sent.

### **Extra item II**

- The Deputy Chair commented on work the government is doing to enable some government data sets to be linked. The work raises questions about access to information that might be confidential or sensitive — of particular interest to ACART is whether information about donor offspring, held by Births, Deaths and Marriages, might become accessible. Members agreed this matter needs to be carefully considered by those doing the data linking work.

### **Extra item III**

- Members agreed to send Karen Reader the agenda pack for the October meeting so that she would be up to date with ACART's work when she attends her first meeting in December. The Deputy Chair offered to meet her to discuss the work programme.

### **Action**



- *The Secretariat to send Dr Reader the October agenda pack.*

**22. Conclusion of meeting**

- 22.1 The next ACART meeting is scheduled for 8 December 2017 and will be held at the Wellington Airport Conference centre.
- 22.2 The meeting closed at 3.00 pm.